

Prevention for Positives

Hawaii's Work Plan For Primary and Secondary HIV Prevention Work with HIV-Positive People and their Partners

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STD/AIDS Prevention Branch
Hawaii Department of Health
Prepared by: Brian White

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The early work of several people and groups has been essential to the launching of the "Prevention for Positives" program in Hawaii. Thanks go out to Richard Barton, Jane Bopp and Timothy Collins for providing a comprehensive needs assessment that established the foundation on which this program has been built. The work of the HIV Prevention Community Planning Group has also been critical in providing the leadership and dedication to support this program for Hawaii's HIV-positive people. The STD/AIDS Prevention Branch staff committed the resources and provided the opportunities to ensure the program would move forward. The results have been seen on the frontline from Hawaii's ASOs who have recruited for this program and provided opportunities for HIV-positive individuals to address challenges in their lives and develop skills around risk reduction and decreasing the spread of HIV.

List of Acronyms

AHP	Advancing HIV Prevention
AIDS	acquired immune deficiency syndrome
ASO	AIDS Service Organization
CDC	U.S. Centers for Disease Control and Prevention
CPG	HIV Prevention Community Planning Group
CSE	commercial sex environment
CTR	counseling testing and referral
DHHS	Department of Health and Human Services
HAART	highly-active anti-retroviral therapy
HIV	human immunodeficiency virus
IDU	injection drug user
ILI	individual level intervention
MSM	men who have sex with men
P4P	Prevention for Positives,
PCM	prevention case management
PCRS	partner counseling and referral services
PSE	public sex environment
SAPB	STD/AIDS Prevention Branch (Hawaii's Department of Health)
STD	sexually-transmitted disease

Executive Summary

The Prevention for Positives (P4P) program in Hawaii is a program for reducing the risk of transmitting HIV. It was developed specifically for people living with HIV and their partners. It uses innovative interventions to reach people most at risk for transmitting HIV through sex or needle sharing. By working directly with HIV positive people, an approach not formally implemented in Hawaii (and most other places in the US) up to this time, a new opportunity and approach is being tried to help stem the unacceptably high rate of new HIV infections.

This document is the working plan for the implementation of the P4P program in Hawaii. It begins by providing the background overview of how the program came about. It briefly examines key issues and opportunities that are the foundation for this program.

National efforts that are emerging around working with positive people are then examined to provide a broad context. Since HIV prevention efforts previously centered on uninfected people, there has to be a shift in how interventions are delivered, to ensure all barriers are addressed and participants' personal needs are met.

This document also looks at the situation in Hawaii and the steps taken that led to the initiation of this program. This section begins with the needs assessment, followed by the prioritization process, the rollout by the Department of Health and the implementation by Hawaii's AIDS service organizations.

The document concludes with goals and objectives that will be used to guide the program as it develops. These were developed from the formal and informal input of people living with HIV, P4P coordinators, agency staff, and Department of Health staff.

By working directly with HIV positive people there are fears of stigmatization and selective targeting. Through supportive, client-centered interventions, as well as being peer-based, there are high hopes that these barriers can be overcome and provide for the reduction in new HIV infections in Hawaii.

Background

Introduction

Primary HIV prevention is made up of all strategies and activities that prevent new HIV infections and thus contribute to the containment of the epidemic. Included categories are counseling, testing, health education, and behavioral risk reduction interventions. The use of science to create biomedical interventions like microbicides, vaccines, post-exposure prophylaxis, and anti-retroviral therapy to reduce HIV viral load also play a role in HIV prevention.¹

Primary prevention for people living with HIV is focused on working with HIV-positive people and their partners to help them stop the spread of HIV and live healthy lives. In Hawaii these efforts are known as “Prevention for Positives” (P4P). It includes working with people who are positive but unaware of their status, those who know their status but are not receiving care and other services, linkages to medical care and social services and support for remaining in and adhering to care, and interventions to initiate and maintain behavior changes in needle sharing and sexual relationships to reduce the risk of transmitting the virus.

Positive people have been doing their own prevention work at the individual level since the beginning of the epidemic. Terje Anderson, HIV positive, and the Executive Director of the National Association of People With AIDS (NAPWA), summarized the situation for HIV positive people in this statement:

Risky behavior by positive people is not the norm. Most of us take extraordinary steps to make sure that we are not infecting our partners, and we’re doing so without a whole lot of support. There aren’t massive public health interventions out there. There aren’t big campaigns supporting us staying safe in our relationships. We’re doing it of our own accord.²

At the agency level support for prevention for HIV positive people has most often been informal and offered without direct funding or specific goals set by public health. Public health is beginning to focus on HIV positive people’s prevention needs. Part of the reason these needs were not focused on in the past has much to do with stigma, discrimination, fear, and rejection that people living with HIV face. Since changing risky behaviors of the infected partner can also prevent a new infection, it makes perfect sense to target both parties in transmission-risky situations.

A traditional intervention with uninfected individuals has involved overcoming participants' barriers to risk reduction. These interventions won't necessarily work with infected people and special consideration must be taken to develop appropriate interventions that address these same barriers they face, plus the additional ones of stigma, fear of stigma, the challenge of dealing with a life threatening illness, symptoms of the disease itself, and the complexities of managing lifelong medical therapy and its side effects. The prevention message must include not only self-protection, but also protection of the partner as well. ³

National Initiative

In 2003 the Centers for Disease Control and Prevention (CDC) introduced Advancing HIV Prevention (AHP) "New Strategies for a Changing Epidemic," as a more comprehensive response in working with HIV positive people. Its aim is to reduce barriers to early diagnosis of HIV infection and increase access to quality medical care, treatment, and ongoing prevention services for HIV-positive persons and their partners. The AHP initiative represents a multi-agency collaboration within the Department of Health and Human Services (DHHS). As described in the April 17, 2003, issue of the CDC Morbidity and Mortality Weekly Report, the initiative consists of four new strategies for HIV prevention:

- Make HIV testing a routine part of medical care
- Implement new models for diagnosing HIV infections outside medical settings
- Prevent new infections by working with persons diagnosed with HIV and their partners
- Further decrease perinatal HIV transmission

In reaction to several key factors that have emerged recently the CDC developed AHP. The fact that general morbidity rates have stabilized is one. For the last decade the US morbidity rate has held steady at 40,000 new infections a year. CDC has set the goal of reducing the incidence of new HIV infections from to 20,000 by 2005. Innovative ways to move past this plateau and reduce new infections must be found to help in meeting this goal. This can be accomplished through helping people to learn their status and access treatment and care. New infections are reduced because the majority of people who learn their positive status take steps to reduce the risk of transmitting the virus. With the recent approval of the use of a blood-stick rapid test is one innovative way to target high-risk people who don't return for their results because of traditional tests take a week or longer for results.

Mortality rates have also held steady. While this is a good thing because it means people are living longer and feeling better, this brings complications. Early on in the epidemic people living with HIV suffered from AIDS related complications, or there were no medications to keep the disease from progressing. People were sick, and they looked and felt it. With the advent of Highly Active Anti-Retroviral Treatment (HAART), after their positive HIV diagnosis people are accessing treatment and care, and generally going on to live healthy, sexual lives for many years. This impacts on the transmission of HIV because it means they are feeling well enough to engage in sex and drug use. Even with their reduced viral loads, without adequate support this can lead to new infections. ⁴

Another factor deals with concerns around the possible increases in HIV incidence in certain populations. This has been seen in the HIV infection rate among men who have sex with men (MSM), a 17% increase in 2002 data from 1999 data. This suggests MSM are interpreting improvements in HIV treatment and care to mean that HIV is no longer a death sentence, but rather a chronic and manageable disease, and the reduced threat means an increase in risk-taking by both positive and negative people. Other populations identified are non-gay-identified men, Hispanic men, African American men and immigrant men.⁵

With people feeling better, living longer and being more active, there is also greater chance for complacency about risk and a relapse into previous behaviors among both positive and negative persons. The recent rise in STDs (sexually transmitted diseases) in surveillance data, and confirmed with recent research studies, has been related to increased risky behavior, including among HIV positive men. This emphasizes the importance of working with people living with HIV who need support to reduce their risk. ⁶

The CDC estimates that 1/3 of new HIV infections come from 75% of people who know their status and 2/3 of new HIV infections come from the 25% of people who don't know their status. The AHP program is built around these simple facts and awareness of how the epidemic has changed with advances in medicine, public perception of risk, and new populations at risk for infection. ⁷

Hawaii

The State of Hawaii represents about 0.43% of the total U.S. population (2000 U.S. Census), and contributes 0.29% of the AIDS cases nationally in 1998-2001. The incidence rate of AIDS reported in Hawaii for 2002 was 10.9 cases per 100,000 population, which is below the U.S. rate of 14.7 cases per 100,000 population. Hawaii ranked twenty-fifth in the nation in 2001. Comparing AIDS cases reported in Hawaii to those reported in the United States as a whole from 1998-2001, a higher proportion of Hawaii's AIDS cases were males (89% vs. 75%), male to male sex exposure (68% vs. 34%), and Caucasians (68% vs. 31%) and Asian/Pacific Islanders (28% vs. 1%). For the 5-year period 1998-2002, the proportion of AIDS cases attributed to MSM declined, while heterosexual contact and undetermined risk increased. Additionally, at the end of 2001 the estimated number of persons living with HIV/AIDS was between 2,617 and 2,924 in Hawaii.⁸

Hawaii's Department of Health STD/AIDS Prevention Branch (SAPB) began to address the concerns and issues around working with HIV-positive people and their partners in 2001 through the implementation of a needs assessment to examine the underlying issues faced by HIV-positive people in Hawaii. The final report "Primary Prevention Needs for People Living with HIV in Hawaii" provided recommendations for designing and implementing interventions to assist people living with HIV to reduce their risk for HIV transmission. The project also had the secondary goal of increasing awareness of such interventions and to mobilize the HIV-positive community and service providers towards implementation of prevention activities for people living with HIV.⁹

Once completed, the needs assessment was used by the Hawaii HIV Prevention Community Planning Group (CPG) to guide them in the process of determining the priority of P4P activities. The CPG established working with positive people as its highest population priority for the 2003 plan. Within this population interventions were prioritized as well, with critical interventions being identified as follows:

- ILIs (individual level interventions)
- PCRS (partner counseling and referral services)
- CTR (counseling testing and referral)
- PCM (prevention case management)

Based on the recommendations of the CPG, the Prevention for Positives program was launched by the SAPB in 2003, with a statewide P4P coordinator position, as well as contracting for P4P coordinator positions with Hawaii's AIDS Service Organizations (ASOs) on Oahu, Big Island, Maui and Kauai.

The role of the P4P statewide coordinator is to provide program guidance and program development assistance to the various ASOs and their P4P coordinators based on agency needs. This position is also responsible for helping the SAPB to implement the other aspects of the CDC's AHP initiative.

The ASO P4P coordinator positions are frontline positions that provide outreach, CTR, PCRS, and ILIs to HIV-positive people on their respective islands. Each ASO has one coordinator position, with the exception of the Life Foundation on Oahu, which has three positions, one each for positive men who have sex with men, women and transgender. The Life Foundation is also contracted for a PCM position to deal with clients that have more intensive needs and referrals to other services, such as mental health and substance use treatment. PCM interventions on the neighbor islands were recognized as being difficult to implement in terms of limited resources and referrals.

People living with HIV and their partners face a myriad of complex issues that cross over traditional boundaries of prevention and care services. In working with them careful attention must be taken to meet their needs.

Some of the complex issues to be addressed were identified in the needs assessment as it examined current research on effective interventions. Risk factors for HIV positive people to transmit HIV included:

- Reduced concerns about unsafe sex with HAART
- Alcohol/drug use before/during sex
- Less perceived control over condom use
- Lower perceived responsibility to protect partner
- Depression/anxiety
- Anger/hostility
- Having an HIV positive sex or needle sharing partner
- Experience with or fear of domestic/other violence
- Poverty and its direct consequences (survival sex, homelessness, etc.)
- Blaming others for one's HIV infection
- Lack of skills in communicating about safer sex/ safer needle sharing
- Not knowing STDs can accelerate HIV infection and/or increase transmission
- Avoidance or wishful thinking coping with HIV in general
- Use of alcohol/drugs to cope with HIV in general
- Assuming partner is HIV positive
- Frequenting PSEs/CSEs (public sex environments/ commercial sex environments)

While no means exhaustive, this list gives a starting point for looking at sources of conflict and trouble for people living with HIV in reducing their risk. It tells us that program flexibility for the intervention itself and for the specific goals of each client is important to ensure objectives are met. The needs assessment also noted research that identified some of the safer behaviors HIV positive people have used to help stop the transmission of HIV:

- Knowledge of one's HIV status
- Intent to use condoms, clean needles, disclose, etc.
- Self-commitment to safer sex/safer needle sharing
- An active behavioral coping style with HIV
- Informed partners (about ones' status, HIV overall)
- Increasing age
- Responsibility or a commitment to others
- Social support
- Peer norms favoring protection of partners/self

The above risk factors and safer behavior correlates outlined in the P4P Needs Assessment are one part of the equation in determining program goals and objectives. It is essential to also include the needs of HIV positive people in Hawaii. These were also gathered in the needs assessment. The table below is an outline of the information gathered:

Concerns	Services	Skills
Stigma	Primary prevention	Talking about sex
Confidentiality	Mental health	Active listening
Peer-led	PCRS	Client-centered
Trust	Substance use	Behavior change theories
Non-judgmental	Disclosure	
Gender affinity		
Sexual orientation affinity		

Strong connections must be formed within each ASO between prevention and care services to ensure referrals are being made to this new program. The strength of these connections varies in each agency. New bridges will need to be built between each ASO, physician offices, and other agencies that provide services to the same population so they can refer and support clients. The program must be flexible to meet the diverse needs of the people being served and the agencies working to implement the P4P program.¹⁰

The Work Plan

Overview

This work plan was created based on the collection of information from various sources by the statewide P4P coordinator. This included the knowledge, experiences and observations made to date by the ASO P4P coordinators and other ASO staff members. It was also collected from SAPB staff from their direct and indirect involvement in the program. While this plan attempts to be comprehensive, allowances and consideration must be given to the fact that the program is embarking upon an endeavor for which there is very little substantive research and experience available to date. Based on this fact, the program was launched with the knowledge that it would be an evolving program, with changes made based on direct experiences in working with HIV positive people and their partners. Thus, this plan is an initial attempt to formalize some goals and objectives to begin to meet the emerging needs of people living with HIV in Hawaii.

Goals and objectives of the Prevention for Positives program are outlined below. These were designed to attempt to comprehensively address the needs of both clients and providers. This outline will be revised and updated as work progresses and new challenges and opportunities are revealed.

Goals and Objectives

Goal 1. ASO P4P coordinators effectively implement direct services to clients.

Objective 1.1: Provide quarterly meetings with all ASO P4P coordinators that facilitate ASO program development and P4P coordinator skill development.

Actions:

- Provide a forum conducive to sharing experiences, challenges and successes in implementing program and working with clients.
- Provide a forum for sharing current local and national P4P materials and data, and information related to the implementation of P4P services.
- Invite presentations from guest speakers with expertise in relevant areas, such as mental health, nutrition, counseling skills, and P4P program development.
- Provide an opportunity for formal and informal networking and knowledge sharing between P4P program coordinators, statewide coordinator and other interested attendees.

Objective 1.2: Provide P4P coordinators with training in essential skills and knowledge to effectively perform duties.

Actions:

- Provide P4P group training for the development of skills in CTR, outreach, PCRS, ILIs, and emerging areas, as well as knowledge of how to deal with issues of stigma, trust, confidentiality, and disclosure and other issues identified.
- The P4P statewide coordinator will work with P4P coordinators individually provide additional opportunities for skills development.

Objective 1.3: Provide P4P coordinators with ongoing support to deal with emerging issues at program, client, and personal level.

Actions:

- Biannual site visits to each ASO by the P4P statewide coordinator for in-depth discussion of issues and opportunities, individual support and the development of specific plans for program implementation appropriate for each agency. Timing of visits determined by consultation between each agency and the P4P statewide coordinator. This will be supported by other SAPB staff site visits.
- Phone calls between the statewide coordinator and the ASO P4P coordinator to check-in, problem solve issues, provide support, and follow up with achieving program goals and objectives for each ASO.
- Statewide coordinator will facilitate informal networking among P4P coordinators statewide through phone, e-mail and other opportunities.
- E-mailing and mailing of appropriate and timely articles, reports, studies and information between coordinators will be encouraged and promoted.
- Develop support materials to help P4P coordinators connect with clients, and develop referrals from other agencies, physicians and clinics. The P4P statewide coordinator will work with each ASO to develop materials appropriate for MSM, TG and Women populations, including business cards, flyers, posters, referral cards, and multimedia presentations.

Goal 2. Develop and implement the Prevention for Positives program at each ASO in an appropriate and effective way for their community.

Objective 2.1: Coordinate P4P services between prevention and care in ASOs.

Actions:

- Determine the need for in-service training, presentations and other activities at each ASO to build awareness and support for the program for effective implementation.
- Develop systems, policies and procedures to ensure the timely and appropriate referral of clients from both prevention and care to the P4P coordinator at each agency.
- Provide P4P program overview at SAPB CTR trainings to ensure widespread knowledge and understanding of program.

Objective 2.2: Build awareness and support for the P4P program in the social services agencies and the community to facilitate referrals to the P4P program.

Actions:

- Identify community agencies that can offer new client referrals to the P4P program and potential venues and opportunities for sharing information and building relationships with them.
- Develop and deliver culturally appropriate presentations, meetings and other activities at these identified community agencies.

Objective 2.3: Build awareness and support of the P4P program in the medical community, including physicians' offices, HIV specialists, and community health clinics to facilitate referrals to the P4P program.

Actions:

- Identify medical providers that can offer new client referrals to the P4P program and potential venues and opportunities for sharing information and building relationships with them.
- Develop and deliver appropriate presentations, meetings and other activities at identified medical providers offices or other venues and provide appropriate support for effective implementation.

Goal 3. Evaluate the effectiveness of the P4P program.

Objective 3.1: Monitor client progress and collect core program data.

Actions:

- Develop a client behavioral risk assessment tool.

- Provide training, support and technical guidance for the P4P coordinators and ASOs use of the evaluation tool.
- Collect data and summarize for use in reports, feedback, CPG prioritization, and future program development.

Objective 3.2: Monitor client satisfaction and feedback information.

Actions:

- Plan and implement a method of collecting client feedback on satisfaction with program intervention and P4P coordinators' skills, knowledge, and abilities.
- Summarize collected information for use in reports and to support choice of future trainings, skills building sessions, CPG prioritization, and program development.

Objective 3.3: Monitor coordinator feedback and evaluation information.

Actions:

- Plan and implement a method of collecting coordinator feedback on personal and program progress.
- Summarize collected information for use in reports and to support choice of future trainings, skills building sessions, CPG prioritization, and program development.

Objective 3.4: Monitor ASO feedback and evaluation information.

Actions:

- Plan and implement a method of collecting ASO feedback on coordinator and program progress.
- Summarize collected information for use in reports and to support choice of future trainings, skills building sessions, CPG prioritization, and program development.

Objective 3.5: Monitor feedback and evaluation information from community members, other community service providers, medical providers and other interested parties.

Actions:

- Plan and implement a method of collecting feedback on program progress.
- Summarize collected information for use in reports and to support choice of future trainings, skills building sessions, CPG prioritization, and program development.

Resources

AIDS Healthcare Foundationwww.aidshealth.org**(323) 860-5200****AIDS Health Project**www.ucsf-ahp.org**(415) 476-3902****AIDS Partnership California**

116 New Montgomery Street, Suite 720

San Francisco, CA 94105-3607

(415) 777-5761 x23 phone**(415) 777-1714 fax**www.aidspartnershipca.org**AIDS Project Los Angeles, Cornerstone Initiative, Education Department**www.apla.org**(213) 201-1600****Asian and Pacific Islander Wellness Center**www.apiwellness.org**(415) 292-3400****California STD/HIV Prevention Training Center**www.stdhivtraining.orgcaptc@dhs.ca.gov**(510) 883-6600****Center for AIDS Intervention Research
Medical College of Wisconsin**www.cair.mcw.edu**(414) 456-7700****Center for AIDS Research
Rollins School of Public Health
Emory University**www.sph.emory.edu**(404) 727-5401****Center for HIV Identification, Prevention, and Treatment Services at UCLA**www.chipts.ucla.educhipts@mednet.ucla.edu

Centers for Disease Control and Prevention

The Prevention for HIV-Infected Persons Project (PHIPP) and Advancing HIV Prevention

www.cdc.gov

CORE Center

www.corecenter.org

(312) 633-4909

Multicultural AIDS Coalition

www.mac-boston.org

(800) 382-1MAC

National Native American AIDS Prevention Center

www.nnaapc.org

(510) 444-2051

Partnership for Health

www.paetc.com/partnershipforhealth.html